Eating-related distress and need for nutritional support of families of advanced cancer patients: A nationwide survey of bereaved family members

AUTHOR(S):

Amano, Koji; Maeda, Isseki; Morita, Tatsuya; Okajima, Yoshiro; Hama, Takashi; Aoyama, Maho; Kizawa, Yoshiyuki; Tsuneto, Satoru; Shima, Yasuo; Miyashita, Mitsunori

CITATION:

Amano, Koji ...[et al]. Eating-related distress and need for nutritional support of families of advanced cancer patients: A nationwide survey of bereaved family members. Journal of Cachexia, Sarcopenia and Muscle 2016, 7(5): 527-534

ISSUE DATE:

2016-12

URL:

http://hdl.handle.net/2433/217402

ORIGINAL ARTICLE

Journal of Cachexia, Sarcopenia and Muscle (2016)
Published online in Wiley Online Library (wileyonlinelibrary.com) **DOI:** 10.1002/jcsm.12102

Eating-related distress and need for nutritional support of families of advanced cancer patients: a nationwide survey of bereaved family members

Koji Amano[1*], Isseki Maeda[2], Tatsuya Morita[3], Yoshiro Okajima[4], Takashi Hama[5], Maho Aoyama[6], Yoshiyuki Kizawa[7], Satoru Tsuneto[8], Yasuo Shima[9] & Mitsunori Miyashita[6]

[1]*Department of Palliative Medicine, Osaka City General Hospital, Osaka City, Osaka, Japan;* [2]*Department of Palliative Medicine, Graduate School of Medicine, Osaka University, Suita City, Osaka, Japan;* [3]*Palliative and Supportive Care Division, Seirei Mikatahara General Hospital, Hamamatsu City, Shizuoka, Japan;* [4]*Department of Psychiatry, Jichi Medical University Saitama Medical Center, Saitama City, Saitama, Japan;* [5]*Palliative Care Team, Osaka Medical Center for Cancer and Cardiovascular Diseases, Osaka City, Osaka, Japan;* [6]*Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Sendai City, Miyagi, Japan;* [7]*Department of Palliative Medicine, Kobe University Graduate School of Medicine, Kobe City, Hyogo, Japan;* [8]*Palliative Care Center, Department of Palliative Medicine, Kyoto University Hospital, Kyoto, Japan;* [9]*Department of Palliative Medicine, Tsukuba Medical Center Hospital, Tsukuba City, Ibaraki, Japan*

Abstract

Background A number of advanced cancer patients are suffering from physical and psychosocial burdens because of cancer cachexia, and these burdens also greatly impact on their family members and relationships between patients and family members. It is necessary to consider the psychosocial impact of cancer cachexia on family members of advanced cancer patients.

Methods A cross-sectional anonymous nationwide survey was conducted involving 925 bereaved family members of cancer patients who had been admitted to 133 inpatient hospices throughout Japan.

Results A total of 702 bereaved family members returned the questionnaires (response rate, 75.9%). Concerning eating-related distress, 'I served what the patient wanted without consideration of calories and nutritional composition' was highest (75.1%), and 'I tried making many kinds of meals for the patient' and 'I was concerned about planning meals for the patient every day' followed (63.0% and 59.4%, respectively). The top 5 of the 19 items were categorized as 'fighting back'. Need for nutritional support was high (72.2%), and need for explanations about the reasons for anorexia and weight loss of patients was moderate (41.4%). Explanatory factor analysis of eating-related distress identified the following four domains: (factor 1) feeling that family members forced the patient to eat to avoid death, (factor 2) feeling that family members made great efforts to help the patient eat, (factor 3) feeling that eating was a cause of conflicts between the patient and family members, and (factor 4) feeling that correct information was insufficient. Results of multiple logistic regression analysis showed that spouse, fair/poor mental status, factors 1, and 4 were identified as independent determinants of major depression {odds ratio [OR] 3.27 [95% confidence interval (CI) 1.24–8.60], $P = 0.02$; OR 4.50 [95% CI 2.46–8.25], $P < 0.001$; OR 2.51 [95% CI 1.16–5.45], $P = 0.02$; OR 2.33 [95% CI 1.13–4.80], $P = 0.02$, respectively}.

Conclusions A number of family members of advanced cancer patients experienced high levels of eating-related distress and had a need for nutritional support.

Keywords Advanced cancer patients; Bereaved family members; Eating-related distress; Nutritional support; Cancer cachexia

Received: 30 November 2015; Accepted: 7 December 2015
**Correspondence to: Koji Amano, Department of Palliative Medicine, Palliative Care Team, Osaka City General Hospital, 2-13-22 Miyakojima-hondori, Miyakojima-ku, Osaka 534–0021, Japan: Tel: +81-6-6929-1221: Fax: +81-6-6929-1091, E-mail: kojiamano4813@gmail.com*

Introduction

A great number of advanced cancer patients are suffering from physical and psychosocial burdens because of cancer cachexia, and these burdens also greatly impact on their family members and relationships between patients and family members.[1–3] Involuntary weight loss is a main symptom of cancer cachexia, and it is linked to the deterioration of physical function, quality

of life, nutritional status, treatment outcomes, and survival in advanced cancer patients.[4–8] Weight loss often follows anorexia and declining food intake, and thus, these are causes of eating-related distress for patients and family members.[1–3] In a survey of 2074 bereaved family members, 78% remembered the anorexia the patient had experienced, and 23% perceived the patient as very distressed by the anorexia.[9] In addition, perspectives on declining food intake often conflict between patients and family members,[1,10,11] and eating habits of patients are influenced by family members.[12,13] These are also causes of eating-related distress for both patients and family members.[10–13] Therefore, it is necessary to consider the psychosocial impact of cancer cachexia,[1–3,10–13] and currently the consensus that nutritional support is important to treat malnutrition due to cancer cachexia is growing.[14]

However, the psychosocial impact of cancer cachexia on family members is poorly understood, and their eating-related distress and need for nutritional support have not been clarified.[1–3] This study was, therefore, designed to investigate the prevalence of eating-related distress and need for nutritional support of family members when the advanced cancer patients become unable to take nourishment orally in inpatient hospices, to categorize eating-related distress of family members, and to explore the association between their eating-related distress and depression.

Methods

The present study was carried out as part of the Japan Hospice and Palliative Care Evaluation Study 3, a cross-sectional anonymous nationwide survey of bereaved family members of cancer patients to evaluate quality of care, quality of death and dying of the patients, and bereaved family outcomes, including depression and complex grief. The main study included bereaved family members of cancer patients who had died in either of the three palliative care settings (general ward, inpatient hospice, or home), and this study included a subpopulation of the main study: bereaved family members of cancer patients who had died in inpatient hospices.

In May 2014, we mailed a questionnaire to the primary caregiver listed in the hospital medical chart of each patient according to previous surveys in Japan.[15,16] If family members did not want to participate, we requested them to return the questionnaire with 'no participation' indicated. We again mailed the questionnaire in June 2014 to non-responding subjects. The completion and return of the questionnaire were regarded as consent to participate in this study. Ethical and scientific validity was confirmed by the institutional review board of each hospital.

Subjects

Primary physicians identified potential participants with the following inclusion criteria: (i) bereaved adult family members of an adult cancer patient who had died in an inpatient hospice (one family member was selected for each patient); (ii) capable of replying to a self-report questionnaire; (iii) aware of the diagnosis of malignancy; and (iv) no serious psychological distress recognized by the primary physician. The last criterion was the same as in previous surveys[15,16] and was adopted on the assumption that primary physicians were able to identify family members suffering from serious psychological distress because they were closely involved in caring for relatives of patients in inpatient hospices.

Questionnaire

The questionnaire for this study was developed by the authors on the basis of a systematic literature review and discussion among the authors.[17–31] Face validity of the questionnaire was confirmed by a pilot test with five bereaved family members and four physicians.

The first question was about the mental status of family members when they were caring for the patient; they were evaluated by the degree of agreement with the following statements on a 4-point Likert-type scale of 1 (good) to 4 (poor).

Questions concerning eating-related distress of family members were composed of 19 items (Table 2); they were evaluated by the degree of agreement with the following statements on a 4-point Likert-type scale of 1 (no) to 4 (frequently).

We then asked whether family members had the need for the following five items, with an answer of 'yes' or 'no': (i) you would like to receive nutritional support for the patient from medical staff members; (ii) you would like to receive sufficient explanations about the reasons for the anorexia and weight loss of the patient; (iii) you would like to be provided with ideas on how to improve the patient's food; (iv) you would like to receive intervention regarding conflict concerning eating and food between you and the patient; and (v) you would like your eating-related distress to be monitored (Table 3).

We also requested family members to answer the Patient Health Questionnaire 9 (PHQ-9), which is a self-administered questionnaire composed of nine items to screen depression. A PHQ-9 score $\geq$ 10 means that an answerer may suffer from major depression.[32–34]

Statistical analyses

Descriptive statistics were used to show the characteristics. We calculated the proportion of family members with a 95% confidence interval (CI) with regard to the questions.

We then used explanatory factor analysis, using the principle method with a promax rotation. According to the results of the factor analysis, attributes with factor loadings less than 0.4 (standardized regression coefficient) were deleted. We also calculated Cronbach's alpha coefficients.

We divided subjects into two categories regarding presence or absence of major depression (PHQ-9 scores ≥ 10 or < 10). Multiple logistic regression analysis was performed to identify independent determinants of major depression using demographics, mental status, and factors of eating-related distress, which were extracted with factor analysis.

Results

In the main study, 175 institutions [general ward (20), inpatient hospice (133), and home (22)] agreed to participate, and 10 715 family members were included. In this study, 133 inpatient hospices and 925 family members were included. Finally, 925 questionnaires were sent to them, and 702 were returned (response rate, 75.9%). Among these, 70 refused to participate, and 74 were excluded because of missing data on eating-related distress. Thus, 558 were analysed for the factor analysis. In addition, 33 and 40 were excluded because of missing data on PHQ-9 and other covariates, such as age, sex, relationship, and mental status, respectively. Thus, 485 were analysed for multiple logistic regression analysis.

Characteristics of participants

Characteristics of participants are shown in Table 1. Characteristics of patients were as follows: the mean age ± standard deviation was 72.7 ± 11.4 years, 55.0% were men, and the mean number of hospital days was 39 ± 53. Upper and lower gastrointestinal tracts (26.9%) were the most common primary cancer site, followed by lung (22.6%) and liver, biliary system, and pancreas (18.6%). As for bereaved family members, the mean age was 60.3 ± 12.0 years, 33.7% were men, 9.9% and 43.9% had good or moderate mental status, respectively, and spouses made up 44.1% and children 37.5%.

Table 1 Characteristics of participants

	Values
Patients	
Age, years	72.7 ± 11.4
Sex	
Male	307 (55.0)
Female	246 (44.1)
Primary cancer site	
Upper and lower gastrointestinal tracts	150 (26.9)
Lung	126 (22.6)
Liver, biliary system, pancreas	104 (18.6)
Urinary system, prostate	45 (8.1)
Gynaecology	31 (5.6)
Head and neck	29 (5.2)
Breast	25 (4.5)
Haematological malignancy	12 (2.2)
Brain	4 (0.7)
Others	32 (5.7)
Hospital days	39 ± 53
Bereaved family members	
Age, years	60.3 ± 12.0
Sex	
Male	188 (33.7)
Female	358 (64.2)
Mental status when they cared for the patient	
Good	55 (9.9)
Moderate	245 (43.9)
Fair	199 (35.7)
Poor	52 (9.3)
Relationship to the patient	
Spouse	246 (44.1)
Child of the patient	209 (37.5)
Others[a]	93 (16.7)

Values are mean ± standard deviation, or *n* (%).
Total percentages do not equal 100% because of missing values.
[a]Others include children-in-law, siblings, and parents of the patient.

Eating-related distress of family members

The prevalence of eating-related distress is shown in Table 2. 'I served what the patient wanted without consideration of calories and nutritional composition' was highest (75.1%), and 'I tried making many kinds of meals for the patient' and 'I was concerned about planning meals for the patient every day' followed (63.0% and 59.4%, respectively). 'I experienced conflict about the patient's daily diet with him/her', 'I felt disregarded when the patient could not eat meals which I made', and 'I thought that the patient could not eat because of a lack of effort on his/her part' were very rare (7.8%, 4.7%, and 2.1%, respectively).

Need for nutritional support of family members

The prevalence of need for nutritional support is shown in Table 3. Their need for nutritional support for their patients was high (72.2%), and need for explanations about the reasons for anorexia and weight loss of patients was moderate (41.4%), while need for intervention regarding conflict between the patient and family members and need for the family member's eating-related distress to be monitored were low (27.8% and 20.8%, respectively).

Factor analysis

In accordance with the aforementioned item reduction procedure, 14 attributes for core domains were selected. The results of the factor analysis for core domains are shown in Table 4. The following four domains were identified: (factor 1) feeling that family members forced the patient to eat to avoid death, (factor 2) feeling that family members made great efforts to help the patient eat, (factor 3) feeling that eating was a cause of conflicts between the patient and family members, and (factor 4) feeling that correct information was insufficient.

Multiple logistic regression analysis

Results of multiple logistic regression analysis performed to identify independent determinants of major depression using demographics, mental status (good/moderate and fair/poor), and the

Table 2 Eating-related distress of family members

Items	Sometimes–frequently *n* (%, 95% confidence interval)	*N*
I served what the patient wanted without consideration of calories and nutritional composition.	402 (75.1, 71–79)	535
I tried making many kinds of meals for the patient.	345 (63.0, 59–67)	547
I was concerned about planning meals for the patient every day.	324 (59.4, 55–63)	546
I felt that a lack of nutrition made the patient's condition worse.	270 (50.9, 47–55)	530
I languished because the patient was disappointed to find that he/she could not eat enough.	262 (48.9, 45–53)	536
I felt it was a natural course of the disease that the patient could not receive enough nutrition and lost weight.	251 (48.5, 44–53)	517
I served a high-calorie and well-balanced diet.	247 (46.8, 43–51)	528
I felt that I did not cherish the patient if I did not make an effort to serve good meals to him/her.	137 (26.5, 23–30)	518
I thought that losing weight resulted from a lack of nutrition and that the patient could gain weight if he/she received enough nutrition.	128 (24.2, 21–28)	528
Friends and relatives recommended many kinds of foods to me for the patient's daily diet, but I was just confused.	125 (23.3, 20–27)	536
The patient was burdened by meals that I kindly made for him/her.	122 (23.1, 20–27)	526
I would like to have consulted with an expert who had specific knowledge of nutritional support about the patient's daily diet.	115 (21.3, 18–25)	539
I felt that I forced the patient to eat.	102 (19.3, 16–23)	527
I felt that the patient tried to enjoy a good meal not for him/herself but for family members.	89 (16.9, 14–20)	527
The patient avoided talking about food and eating with family members.	82 (15.6, 12–19)	526
It was useless for me to consult about the patient's daily diet with medical staff members.	52 (10.1, 8–13)	511
I experienced conflict about the patient's daily diet with him/her.	42 (7.8, 6–10)	537
I felt disregarded when the patient could not eat meals which I made.	25 (4.7, 3–7)	528
I thought that the patient could not eat because of a lack of effort on his/her part.	11 (2.1, 1–3)	533

Table 3 Need for nutritional support of family members

Items	*n* (%, 95% confidence interval)	*N*
You would like to receive nutritional support for the patient from medical staff members. (Yes)	386 (72.7, 69–76)	531
You would like to receive sufficient explanations about the reasons for anorexia and weight loss of the patient. (Yes)	235 (41.4, 37–45)	568
You would like to be provided with ideas on how to improve the patient's food. (Yes)	177 (31.2, 27–35)	568
You would like to receive intervention regarding conflict concerning eating and food between you and the patient. (Yes)	158 (27.8, 24–32)	568
You would like your eating-related distress to be monitored. (Yes)	118 (20.8, 17–24)	568

four factors of eating-related distress are shown in Table 5. Data for factors 1, 2, and 4 were classified into three categories (no, occasionally/sometimes, and frequently) and data for factor 3 into two categories (no and occasionally/sometimes/frequently) after merging due to lack of data.

Spouse, fair/poor mental status, factors 1, and 4 were identified as independent determinants of major depression [odds ratio (OR) 3.27 (95% CI 1.24–8.60), $P = 0.02$; OR 4.50 (95% CI 2.46–8.25), $P < 0.001$; OR 2.51 (95% CI 1.16–5.45), $P = 0.02$; OR 2.33 (95% CI 1.13–4.80), $P = 0.02$, respectively] (Table 5).

Discussion

Eating-related distress and need for nutritional support of family members of advanced cancer patients have not been clarified. To the best of our knowledge, this study is the first large quantitative survey designed to investigate the prevalence of eating-related distress and need for nutritional support of family members, to categorize their eating-related distress, and to explore the association between their eating-related distress and depression.

In this study, nutritional support means that medical staffs with specific nutrition, such as trained physicians, dietitians, pharmacists, and nurses, provide individualized and tailored nutritional support and advice to each patient. Eating-related distress is emotional strains in advanced cancer patients and their family members caused by anorexia and weight loss of patients. Negative impact of cancer cachexia is simply defined as disease-related anorexia and weight loss.

In studies investigating eating-related distress of family members of advanced cancer patients, their responses to

Table 4 Factor validity of eating-related distress of family members: four core domains ($n = 558$)

	Standardized regression coefficients				
	F1	F2	F3	F4	Communality
F1. Feeling that family members forced the patient to eat to avoid death (mean = 2.03, SD = 1.12, Cronbach's $\alpha = 0.77$)					
I felt that a lack of nutrition made the patient's condition worse.	**0.701**	0.025	−0.158	0.208	0.599
I felt that the patient tried to enjoy a good meal not for him/herself but for family members.	**0.620**	−0.047	0.062	−0.133	0.455
I felt that I forced the patient to eat.	**0.602**	−0.042	0.297	−0.072	0.647
I thought that losing weight resulted from a lack of nutrition and that the patient could gain weight if he/she received enough nutrition.	**0.583**	0.038	0.044	0.149	0.484
I languished because the patient was disappointed to find that he/she could not eat enough.	**0.466**	−0.220	0.074	−0.012	0.442
F2. Feeling that family members made great efforts to help the patient eat (mean = 2.95, SD = 1.08, Cronbach's $\alpha = 0.75$)					
I tried making many kinds of meals for the patient.	0.083	**−0.773**	−0.033	0.063	0.683
I was concerned about planning meals for the patient every day.	0.054	**−0.722**	0.047	0.158	0.701
I served what the patient wanted without consideration of calories and nutritional composition.	−0.045	**−0.550**	−0.010	−0.038	0.289
F3. Feeling that eating was a cause of conflicts between the patient and family members(mean = 1.37, SD = 0.74, Cronbach's $\alpha = 0.68$)					
I experienced conflict about the patient's daily diet with him/her.	−0.085	−0.044	**0.673**	0.071	0.468
I felt disregarded when the patient could not eat meals which I made.	−0.010	−0.007	**0.641**	−0.001	0.447
The patient was burdened by meals that I kindly made for him/her.	0.272	−0.131	**0.537**	0.047	0.643
I thought that the patient could not eat because of a lack of effort on his/her part.	0.059	0.057	**0.441**	0.018	0.273
F4. Feeling that correct information was insufficient (mean = 1.77, SD = 1.00, Cronbach's $\alpha = 0.66$)					
Friends and relatives recommended many kinds of foods to me for the patient's daily diet, but I was just confused.	0.002	−0.039	0.083	**0.704**	0.568
I would like to have consulted with an expert who had specific knowledge of nutritional support about the patient's daily diet.	0.033	−0.061	0.038	**0.621**	0.472
Cumulative proportion, 47.7%					

F#, Factors 1 to 4; SD, standard deviation; Cronbach's α, Cronbach's alpha coefficients.
Boldfaced numbers indicate attributes belonging to each domain.

Table 5 Factors of family members related to depression ($n = 485$)

	Odds ratio (95% confidence interval)	*P*
Age, per 10 years	0.97 (0.73–1.30)	0.86
Female	1.09 (0.61–1.96)	0.76
Relationship to the patient		
Spouse	3.27 (1.24–8.60)	0.02
Child of the patient	1.13 (0.39–3.30)	0.82
Others[a]	1.00 (reference)	
Mental status when they cared for the patient		
Good–moderate	1.00 (reference)	
Fair–poor	4.50 (2.46–8.25)	<0.001
Feeling that family members forced the patient to eat to avoid death		
Occasionally–sometimes	0.87 (0.45–1.69)	0.69
Frequently	2.51 (1.16–5.45)	0.02
Feeling that family members made great efforts to help the patient eat		
Occasionally–sometimes	1.17 (0.35–3.93)	0.79
Frequently	1.25 (0.38–4.11)	0.72
Feeling that eating was a cause of conflicts between the patient and family members		
Occasionally–frequently	1.46 (0.73–2.95)	0.29
Feeling that correct information was insufficient		
Occasionally–sometimes	0.83 (0.42–1.61)	0.57
Frequently	2.33 (1.13–4.80)	0.02

[a]Others include children-in-law, siblings, and parents of the patient.
Depression was diagnosed when the total score of the Patient Health Questionnaire 9 was 10 points or greater.

declining food intake and weight loss of patients were described as three separate sub-processes: 'fighting back', 'letting nature take its course', or 'waffling', the latter referring to vacillating between the first two patterns.[25–27] In this study, the top 5 of the 19 items (48.9–75.1%) were categorized as 'fighting back' and the sixth item (48.5%) as 'letting

nature take its course'. Thus, the sub-process of 'fighting back' by family members can cause distress.

This study revealed that over 70% of family members needed nutritional support for their patients and over 40% would like to have received sufficient explanations about the reasons for anorexia and weight loss of the patient. This is consistent with a previous study, in which the main causes of psychosocial burdens of advanced cancer patients and family members were lack of knowledge about cancer cachexia, unsuccessful attempts to increase body weight, and expected occurrence of death.[2] A study reported eating-related distress when the reality of eating differed from the expectations of eating.[20] In our previous preliminary study, specific support, such as 'attention to patient's distress about eating' and 'explanation of the reasons for anorexia and weight loss', was needed by many patients, and it might alleviate their eating-related distress. The study also suggested that hopelessness, fretting, and a shortage of information aggravated their distress.[31]

In Japan, inpatient hospices anorexic–cachectic cancer patients are often treated with drugs, for example, corticosteroids, while they scarcely receive specific nutritional support maybe because medical staff members in hospices tend to withhold aggressive care. Eating-related distress of patients and their family members in Japan may be induced against such background. In addition, the identified four domains (Table 4) indicated where the focus of intervention for eating-related distress of family members should be.

This study, as well as previous studies, indicated that medical staff members might contribute to the relief of patients and family members by giving advice on how to avoid futile activities and by explaining why anorexia and weight loss become irreversible.[23,31] Thus, we should explain the mechanism of cancer cachexia as simply as possible, and this may contribute to the relief of patients and family members by paying attention to their distress and by appreciating their efforts to cope.

In this study, the experience of conflicts over food was one of the lowest frequency items (7.8%) among the 19, while the need for intervention in such conflicts was moderate (27.8%). It seems that overt emotional conflicts over food in families in Japan inpatients hospices seldom occur despite family members' latent distress. In contrast, Reid *et al.*[10] suggested that reduced dietary intake frequently became a source of conflict between patients and their family members in inpatients and outpatients units, while the prevalence of conflict was unclear.

Patients ate not because they wanted food but because they wanted to satisfy their family members, who were encouraging them to eat. Family members often experienced feelings of rejection of their affection when food was refused by patients.[9,10] Changes in food preferences and eating habits induced conflict between patients and family members, because they failed to see weight loss as an inevitable consequence of cancer cachexia. The family members unintentionally caused unnecessary pressure on patients to eat. While patients often felt dejected and harassed because of this conflict, family members also suffered. Contrary to family members' intention, their approach to the eating problem can become a barrier to food intake.[10,18] In addition, anorexia is one of the most distressful symptoms in the last week of life in advanced cancer patients, but family members fail to rate it as important.[29] A qualitative study suggested that perspectives of patients might not necessarily be shared by their family members and that anorexia of the patients was indeed a source of eating-related distress and conflict within the family.[35]

We can support patients and family members in managing conflict over food. We can draw from our own experiences of patients and family members who have found effective ways of managing conflict. Sharing this experiential knowledge can demonstrate that disagreements over food can be temporary and present ideas that enable patients and family members to see new ways of managing their problems.[18]

Our results imply that spouses have a higher risk of depression by loss of their partner. Negative impacts of cancer cachexia affect cooking at home, the couple's daily eating habits, and their spousal relationship.[1] When food was rejected by patients, the family members, especially women, responded in two ways. First, they experienced feelings of guilt and fault, because they believed that not offering food might have been viewed as neglect on their part. Second, they became angry when patients declined food that they prepared.[9,10] Another study suggested that family members' eating-related distress was more pronounced in women than in men because women expressed their caring through the preparation and serving of food.[35] Female partners were more concerned about male patients' weight loss than patients themselves, and patients felt more pressure to eat from partners than they had estimated.[23] Our results also imply that bereaved family members who feel that they forced the patient to eat to avoid death and those who feel that correct information was insufficient have a higher risk of bereavement depression.

Although it seems to be difficult to identify family members who may be suffering from depression, this study indicates that a female spouse who is excessively concerned about the patient's daily diet without sufficient knowledge has a higher risk of depression by loss of her partner. Thus, we should give advice on how to avoid futile activities and explain why anorexia and weight loss become irreversible to prevent bereaved family members' depression.

Despite the strengths of a large multicenter study and high response rate, this study has several limitations. First, the survey subjects were family members, and care strategies suggested from this study are for family members. The distress of a symptom is unique to the patient and most accurate when described by the patient. Family members tend to overrate the intensity of symptoms[29] and experience more eating-related distress than patients (87% versus 36%).[36] We do not, however, believe that this is a weakness of this study because

family members are a main subject for palliative care. Second, the study subjects were limited to family members of patients admitted to inpatient hospices, and non-responding subjects were not included in the analysis, so the findings cannot be generalized to other settings. Third, we cannot affirm that the patients of responding subjects were suffering from cachexia. However, upper and lower gastrointestinal tracts (26.9%) were the most common primary cancer site, followed by lung (22.6%) and liver, biliary system, and pancreas (18.6%) in this study. This may indicate that most patients were suffering from cachexia. Fourth, there may have been recall bias because of the retrospective design of the study, including self-assessment of mental state. Fifth, the questionnaire for this study had not been validated. However, there is no validated tool to estimate eating-related distress of advanced cancer patients and their family members. Sixth, several yes/no questions have the potential to be affected by acquiescence bias. However, results of four items of five with an answer of 'yes' or 'no' were not high (Table 3). This may mean that influence of acquiescence bias was slight. Seventh, we cannot compare backgrounds between participating and non-participating subjects, and thus there might be a systematic bias.

Conclusions

A number of family members of advanced cancer patients admitted to inpatient hospices experienced high levels of eating-related distress and had a need for nutritional support for their patients. Sufficient explanation about the reasons for anorexia and weight loss of patients (i.e. mechanism of cancer cachexia) may contribute to the relief of patients and family members and alleviate their eating-related distress. Further surveys need to be developed to establish indicators and outcomes of care for eating-related distress of advanced cancer patients and family members.

Acknowledgements

The authors have read and complied with the principles of ethical authorship of the Journal of Cachexia, Sarcopenia and Muscle.[37]

This study was part of The Japan Hospice and Palliative Care Evaluation Study, funded by Japan Hospice Palliative Care Foundation and with corporation of Hospice Palliative Care Japan.

Conflict of interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and publication of this article.

References

1. Hopkinson JB. Psychosocial impact of cancer cachexia. *J Cachexia Sarcopenia Muscle* 2014;**5**:89–94.
2. Oberholzer R, Hopkinson JB, Baumann K, Omlin A, Kaasa S, Fearon KC, *et al*. Psychosocial effects of cancer cachexia: a systematic literature search and qualitative analysis. *J Pain Symptom Manage* 2013;**46**:77–95.
3. Reid J, Santin O, Porter S. The psychological and social consequences of cachexia in patients with advanced cancer: a systematic review. Cachexia Conference; Boston, USA. *J Cachexia Sarcopenia Muscle* 2012;**3**:281–301.
4. Fearon K, Glass DJ, Guttridge DC. Cancer cachexia: mediators, signaling, and metabolic pathways. *Cell Metab* 201216, August;**8**:153–166.
5. Fearon KC, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, *et al*. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol* 2011;**12**:489–495.
6. Fearon KC. Cancer cachexia and fat-muscle physiology. *N Engl J Med* 2011;**365**:565–567.
7. Laviano A, Seelaender M, Rianda S, Silverio R, Rossi Fanelli F. Neuroinflammation: a contributing factor to the pathogenesis of cancer cachexia. *Crit Rev Oncog* 2012;**17**:247–251.
8. Tisdale MJ. Mechanisms of cancer cachexia. *Physiol Rev* 2009;**89**:381–410.
9. Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliat Med* 1995;**9**:295–305.
10. Reid J, McKenna H, Fitzsimons D, McCance T. The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *Int J Nurs Stud* 2009;**46**:606–616.
11. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;**36**:439–445.
12. Hopkinson JB. Carers' influence on diets of people with advanced cancer. *Nurs Times* 2008;**104**:28–29.
13. Hopkinson JB. How people with advanced cancer manage change in eating habits. *J Adv Nurs* 2007;**59**:454–462.
14. Aapro-Piancentini M, Arends J, Bozzetti F, Grunberg SM, Herrstedt J, *et al*. Early recognition of malnutrition and cachexia in the cancer patient: a position paper of a European School of Oncology Task Force. *Ann Oncol* 2014. doi:10.1093/annonc/mdu085.
15. Yamagishi A, Morita T, Miyashita M, Sato K, Tsuneto S, Shima Y. The care strategy for families of terminally ill cancer patients who become unable to take nourishment orally: recommendations from a nationwide survey of bereaved family members' experiences. *J Pain Symptom Manage* 2010;**40**:671–683.
16. Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y. A nationwide survey of quality of end-of-life cancer care in designated cancer centers, inpatient palliative care units, and home hospices in Japan: the J-HOPE study. *J Pain Symptom Manage* 2015;**50**:38–47.
17. Hopkinson JB, Okamoto I, Addington-Hall JM. What to eat when off treatment and living with involuntary weight loss and cancer: a systematic search and narrative review. *Support Care Cancer* 2011;**19**:1–17.
18. Hopkinson JB, Wright DNM, Foster C. Management of weight loss and anorexia. *Ann Oncol* 2008;**19**:289–293.
19. Hopkinson JB. The emotional aspects of cancer anorexia. *Curr Opin Support Palliat Care* 2010;**4**:258.
20. Hopkinson JB, Corner J. Helping patients with advanced cancer live with concerns about eating: a challenge for palliative care

professionals. *J Pain Symptom Manage* 2006;**31**:293–305.
21. Hopkinson JB, Wright DNM, McDonald JW, Corner JL. The prevalence of concern about weight loss and change in eating habits in people with advanced cancer. *J Pain Symptom Manage* 2006;**32**:322–331.
22. Hopkinson JB, Wright D, Corner J. Exploring the experience of weight loss in people with advanced cancer. *J Adv Nurs* 2006;**54**:304–312.
23. Strasser F, Binswanger J, Cemy T, Kesserlring A. Fighting a losing battle: eating related distress of men with advanced cancer and their female partners: a mixed methods study. *Palliat Med* 2007;**21**:129–137.
24. Reid J, McKenna HM, Fitzsimons D, McCance TV. An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals. *Eur J Cancer* 2010;**19**:682–689.
25. McClement S. Cancer anorexia-cachexia syndrome: psychological effect on the patient and family. *J Wound Ostomy Continence Nurs* 2005;**32**:264–268.
26. McClement SE, Degner LF, Harlos M. Family responses to declining intake and weight loss in a terminally ill relative. Part 1: fighting back. *J Palliat Care* 2004;**20**:93–100.
27. McClement S, Degner L, Harlos M. Family beliefs regarding the nutritional care of a terminally ill relative: a qualitative study. *J Palliat Med* 2003;**6**:737–748.
28. Shragge JE, Wismer WV, Olson KL, Baracos VE. Shifting to conscious control: psychosocial and dietary management of anorexia by patients with advanced cancer. *Palliat Med* 2007;**21**:227–233.
29. Oi-Ling K, Man-Wah DT, Kam-Hung DN. Symptom distress as rated by advanced cancer patients, caregivers and physicians in the last week of life. *Palliat Med* 2005;**19**:228–233.
30. Malia C, Bennett MI. What influences patients' decisions on artificial hydration at the end of life? A Q-methodology study. *J Pain Symptom Manage* 2011;**42**:192–201.
31. Amano K, Maeda I, Morita T, Tatara R, Katayama H, Uno T, *et al*. Need for nutritional support, eating-related distress and experience of terminally ill patients with cancer: a survey in an inpatient hospice. *BMJ Supportive Palliative Care* 2015;**0**:1–4, doi:10.1136/bmjspcare-2014-000783.
32. Kroenke K, Spitzer R, Williams J. The PHQ-9 validity of a brief depression severity measure. *J Gen Intern Med* 2001;**16**:606–613.
33. Muramatsu K, Miyaoka H, Kamijima K, Muramatsu Y, Yoshida M, Otsubo T, *et al*. The Patient Health Questionnaire, Japanese version: validity according to the mini-international neuropsychiatric interview-plus. *Psychol Rep* 2007;**101**:952–960.
34. Inagaki M, Ohtsuki M, Yonemoto N, Kawashima Y, Saitoh A, Oikawa Y, *et al*. Validity of the Patient Health Questionnaire (PHQ)-9 and PHQ-2 in general internal medicine primary care at a Japanese rural hospital: a cross-sectional study. *Gen Hosp Psychiatry* 2013;**35**:592–597.
35. Holden CM. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and family. *Hosp J* 1991;**7**:73–84.
36. Hawkins C. Anorexia and anxiety in advanced malignancy: the relative problem. *J Hum Nutr Diet* 2000;**13**:113–117.
37. von Haehling S, Morley JE, Coats AJS, Anker SD. Ethical guidelines for publishing in the Journal of Cachexia, Sarcopenia and Muscle: update 2015. *J Cachexia Sarcopenia Muscle* 2015;**6**:315–316.